

Family Survivorship for Patients with Cancer: Existing Knowledge and Future Directions

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Facts and Figures

- 10.5 million cancer survivors—therefore at least that many family members involved
- 66% of patients diagnosed today will be alive in 5 years—need family care
- 903,078 diagnosed this year –caregivers role over next 5 years

Survivorship

Problems/Concerns –Patient

- Genetics/Health Practices
- Fertility/Sexuality
- Cognitive
- Dyadic Interaction- coping, communication, problem solving, decision making
- Employment/Insurance
- Uncertainty post treatment
- Economic hardships

All are relevant to the Family Caregiver



Survivorship and the Family

- Affects each family member
- Changes during treatment period: may or may not lead to changes in family roles & daily functioning during survivorship
- Affects family communication-family members want to move on-be done with cancer, patient can't forget
- Fearful and uncertainty about future



What Survivor Caregivers do

- Who knows—sparse research except in palliative and end of life
- Serve as health advocates for patient
- Monitor patients follow-up
- Seek ways to return to “new normal”
- Maintain family



What Caregivers Are Required To Do

- Assume shared responsibilities for decisions/problem solving
- Monitor and manage symptoms and late side effects, detect early complications, deal with residual effects
- Monitor ongoing care and follow-up
- Receive little information assistance or guidelines from professionals



Knowledge About Caregiving During Treatment

- Risk factors for caregiver burden, distress and negative reaction
- Examined stress and coping
- Who cares and some content on tasks of care
- Rewards/gains occur from care –all care is not negative
- Not all caregivers are burdened or depressed, some caregivers do quite well



Caregivers Own Negative Emotional Effects into Survivorship

- Depression (20-30%)
- Coping and Adjustment
- Distress lasts beyond patient's active treatment
- Unsure how these negative responses extend into survivorship
- Uncertainty



Stressors for Families in Care Situation

- Caregiver depression and burden are related to patient negative affective states
- Stable intensive care is not as stressful as is the distress from transition (whether improving or deteriorating)
- Change in the caregiver recipient/ caregiver relationship –communication
- Regret with past decisions (caregiver or patient)
- Incongruence between reality and expectations of returning to normal



Stressors for Caregivers

- Uncertainty of future
- Decisional conflicts
- New late effects— new reaction and adjustment
- Residual effects or late effects (e.g. Lymphedema)
- Delay in patient return to function
- Interference with personal activities—want to return to new normal
- Safety Net gone
- Patient's negative behaviors (Cognitive impairment and incontinence)



Economic Situation

- Employment and health insurance –caregivers change
- Financial debt-may be altered long term
- Job re-engineering (caregiver)
- Out-of-pocket cost for long-term medications and other care
- Depletion of savings –also a late effect



Follow-up Care & Surveillance

- Own health care practices and family member health advocacy (Bowman)
- Little guidance on survivorship period-turned over to primary care
- Inconsistent follow-up care/no guidelines
- Emotional sequela unknown
- Compliance with lifelong or multi-agent therapeutic agents
- Relinquishing the caregiver role from treatment phase



Interventions

- No interventions found to address patient and caregiver transition into survivorship
- What type of interventions will facilitate transition and when should they be implemented?
- What change occurs in family structure, lifestyle modification and health promotion
- Does caregiver interventions during active treatment prevent caregiver distress in survivorship phase?



Survivorship Care Plan for Family Needed

- Summary of treatment and needed follow up
- Transitions to Primary Care
- Access to quality follow up care and surveillance
- Monitoring of late effects-menopausal, bone loss & osteoporosis, sexual problems, cardiovascular
- Insurability & employment (patient or caregiver)
- Education & information-tailored to situation
- Compliance with medications and follow-up
- Preventive practices and health promotion
- Rehabilitation and need for psychosocial services



Gaps in Knowledge –Future Research

- What is family role in survivorship phase?
- What is long-term impact on caregiver health of caregiving 5 to 10 years later
- Is a successful caregiver during active therapy the successful caregiver in survivorship?
- Is the transition period shortened if the caregiver is a partner in care with the formal care system?
- How can caregivers influence patients transition into the survivorship phase?
- All knowledge and skills are not equal –ability to do physical care does not translate into transition care – what skills needed?



Gaps in Knowledge –Future Research

- How do minority, ethnic groups, and low-income caregivers response to survivorship care?
- What mechanisms can be used to reach the overwhelmed caregivers transitioning –intervention trial
- What role does caregiver have with primary care provider over survivorship plan of care?
- How do financial & economic sacrifices during treatment influence survivorship phase for caregivers?
- Does the proposed “family” survivorship plan of care work?



Gaps in Knowledge –Future Research

- What is the response of the caregiver to late effects?
- How does caregiver stress, burden or depression affect their decision-making and problem-solving involvement in care
- What are the financial costs (informal) and opportunity costs to families?
- How does the impact on caregiver vary if major residual effects vs. new late effects?



Gaps in Knowledge –Future Research

- How does the quality of care during therapy affect the survivorship period?
- What patient outcomes during survivorship are most sensitive to family support?
- How can technology assist family caregiver in their care? (reduced distress,)(web, monitors, etc.)
- What is the OOP Cost of cancer care in the survivorship period?
- What are responses of non-spouses caregivers to continuing disability and late effects?



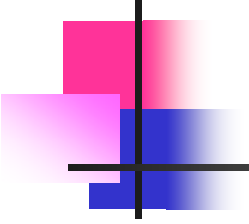
Gaps in Knowledge –Future Research

- How does life stage variation affect caregiver needs during survivorship (youth, young adult, adult, elderly)
- What differences exist in caregiving when there are different family configurations (gay and lesbian, unmarried)?
- Will interventions targeted toward caregivers who are distressed, reduce distress during survivorship?
- What “type” of interventions are needed for caregiver transitions (information/education, psychoeducational etc)?



Gaps in Knowledge–Future Research

- Does early caregiver intervention targeted to transitions contribute positively to patient outcome?
- What is relationships between informal care and patient long term overcomes, e.g., symptom control, complication, functional return?



Family caregivers are a major resource- we need the science to understand how they contribute to the survivors care –and they need to be supported

At the next 10 year celebration perhaps we can boldly say to “ Who cares for the caregiver?”

“We all do.”